

Research Updates

in kidney and urologic health

National Kidney and Urologic Diseases Information Clearinghouse

FALL 2003



National
Institute of
Diabetes and
Digestive
and Kidney
Diseases

NATIONAL
INSTITUTES
OF HEALTH

Clinical Trials in Kidney and Urologic Disease Set for Recruitment

Focus on Chronic Renal Insufficiency, BPH Therapies, and Dialysis Access

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) conducts and supports research on many of the most serious diseases affecting public health. NIDDK's Division of Kidney, Urologic, and Hematologic Diseases (KUH) provides research funding and support for basic science and clinical research studies of the kidney and urinary tract and disorders of the blood and blood-forming organs.

John Kusek, Ph.D., directs the Clinical Trials Program, which works in concert with other KUH programs to develop and manage cooperative clinical trials to prevent or retard major

CLINICAL TRIALS, continued on page 6



Inside This Issue...

Kidney and Urologic Organizations Offer Wealth of Information	2
New Publications From NKUDIC.....	9
NKF's New Study Shows Possible Links Between Smoking and Kidney Disease.....	10
New in CHID	11
NKDEP Launches Programs to Prevent Kidney Disease Among African Americans	12
What You Need to Know About NKUDIC Online	13
Upcoming Conferences and Workshops.....	13
NKUDIC Wins Plain Language Awards	16

New GFR Calculation Facilitates Monitoring of Kidney Function

Laboratories Urged to Include GFR Calculation in Routine Blood Work

Researchers and clinicians agree that the most accurate measure of kidney function is the glomerular filtration rate (GFR). Measuring GFR used to require a 24-hour urine collection and a blood sample, thus making regular measurements impractical. In recent years, however, researchers in the Modification of Diet in Renal Disease (MDRD) trial, sponsored by the

GFR CALCULATION, continued on page 8



U.S. Department
of Health and
Human Services

Kidney and Urologic Organizations Offer Wealth of Information

New Print Materials and Websites Help Patients Find Answers

In the past, a patient with a kidney disease or a urinary problem might complain about the lack of understandable materials on the subject. The Internet has made finding information easier for patients, but wide availability of materials does not guarantee their reliability.

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) works to help patients and their families find answers to their questions about kidney and urologic diseases. The clearinghouse fulfills this mission in two ways:

- developing health information materials for patients
- referring patients to reliable sources of information and support

NKUDIC works with a coordinating panel whose members represent national professional societies, and patient-advocacy organizations concerned with kidney and urologic health. While many of the organizations have missions supporting research or professional development for health care providers, most also support health information for the public. The following organizations work with NKUDIC and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and share the goal of providing science-based information about kidney and urologic diseases to patients and the public.

American Association of Kidney Patients



www.aakp.org

The American Association of Kidney Patients (AAKP) offers the AAKP Patient Plan, a series of booklets, checklists, and newsletters designed to guide patients through the stages of chronic kidney disease and end-stage renal disease. AAKP also provides a number of programs and services specifically for those who have chronic kidney disease but are not yet on dialysis. *Kidney Care: Finding Your Strength* is

a program that offers free local educational sessions for people who have kidney disease or are approaching it. AAKP also publishes *aakpRENALIFE* magazine and the *Renal Flash* electronic newsletter.

American Foundation for Urologic Disease/American Urological Association



www.afud.org
www.auanet.org
www.urologyhealth.org

The American Foundation for Urologic Disease and the American Urological Association have developed *UrologyHealth.org*, a patient education website with information about a wide range of conditions treated by urologists. Visitors can use a navigation bar to browse through general topics in adult and pediatric urology and find pages on specific conditions such as prostatitis or enuresis. Difficult terms are underlined so that the reader can click on the word to view a pop-up definition, which can also be found in an A-to-Z glossary.

American Kidney Fund



www.akfinc.org

In addition to providing direct financial assistance to patients, the American Kidney Fund (AKF) supports a number of educational programs. The AKF established the Minority Health Outreach Program (MHOP) to address the alarming rate of chronic kidney disease and related conditions in African-American and Hispanic communities. The program offers medical screening, nutrition and fitness presentations, and followup services, including medical referrals and public education materials. Titles of AKF brochures include “Kidney Disease Strikes African Americans” and “African Americans and Diabetes.” AKF’s latest brochure is titled “What I Need to Know About Preventing Complications of Chronic Kidney Disease.”

American Nephrology Nurses' Association



www.annanurse.org

The American Nephrology Nurses' Association (ANNA) works to advance nephrology nursing practice and positively influence outcomes for patients with kidney and other diseases. Special Interest Groups (SIGs) within ANNA promote education and practice standards for hemodialysis, peritoneal dialysis, transplantation, and pediatric nephrology. The SIGs have developed a series of fact sheets for patients and family members. Parents of children with kidney disease can give the fact sheets to school administrators to help explain their child's condition. These fact sheets can be downloaded from the ANNA website by clicking on "Practice" on the navigation bar.

American Society of Nephrology



www.asn-online.org

The American Society of Nephrology (ASN) works to enhance and assist the study and practice of nephrology, to provide a forum for promulgating research, and to meet the professional and continuing education needs of its members. ASN worked with the NIDDK to establish the Kidney Disease Clinical Studies Initiative (KDCSI), which offers support for data analysis, protocol development, and formation of consortia to plan clinical studies. ASN members serve on the KDCSI Steering Committee. The ASN is also working with the National Kidney Foundation and the Renal Physicians Association to sponsor a workshop to develop an action plan for dealing with the growing number of people in the early stages of chronic kidney disease.

American Society of Pediatric Nephrology

www.aspneph.com



The Clinical Affairs Committee of the American Society of Pediatric Nephrology (ASPN) provided editorial review for NIDDK's new series of fact sheets on kidney disease in children. ASPN members have also reviewed patient fact sheets for the National

Kidney Foundation. The ASPN is participating in the steering committee of the National Kidney Disease Education Program to ensure that it addresses pediatric issues. The ASPN publishes *KIDney NOTES*, a newsletter that keeps pediatric nephrologists informed on legislative issues, research opportunities, and professional meetings.

American Society of Transplantation



www.a-s-t.org

The American Society of Transplantation (AST) offers a forum for the exchange of knowledge, scientific information, and expertise in the transplantation field. The AST website provides a patient education section where visitors can download brochures that explain the procedure for receiving a transplanted kidney, liver, heart, or lung and how to keep a transplanted organ healthy. Available titles include "Getting a New Kidney: Facts About Kidney Transplants," "Keeping Your New Kidney Healthy: Facts About Transplant Medications," and "Can Anyone Be an Organ Donor? Facts About Living Organ Donation."

American Urogynecologic Society



www.augs.org

The American Urogynecologic Society (AUGS) is dedicated to research and education in urogynecology and to improved care for women with lower urinary tract disorders. The patient information section of the AUGS website helps women identify their problem through a series of links with labels such as "I have to urinate frequently"; "I leak when I cough, exercise, laugh, or sneeze"; "I can't hold my urine when I get the urge to go"; or "Since the birth of my baby, I am leaking urine." Additional fact sheets deal with sexuality and incontinence, overactive bladder, stress incontinence, and surgery for incontinence. An additional fact sheet answers the question "What Is a Urogynecologist?" The website also helps visitors locate a urogynecologist in their area.

Interstitial Cystitis Association



www.ichelp.org

The Interstitial Cystitis Association (ICA) offers information and support to patients with IC and their families, educates the medical community about the disease, and promotes research to find effective treatments for IC and, ultimately, a cure. The ICA publishes two quarterly newsletters: the *ICA Update*, for patients and general audiences, and the *ICA Physician Perspectives*, with news and information for health professionals. *Café ICA* is a monthly online news digest. The ICA website also provides sections on treatment, research, and clinical trials. The ICA Question Corner allows visitors to submit questions and view responses to others' questions. Patients can use the ICA website to find local support groups and learn about self-help strategies.

Life Options Rehabilitation Program



www.lifeoptions.org

The nonprofit Medical Education Institute, Inc., administers the Life Options Rehabilitation Program to help people on dialysis live long and well. Life Options publishes the quarterly newsletter *Renal Rehabilitation Report* for patients and health professionals; it deals with research, policy issues, and stories about successful renal rehabilitation initiatives on the local, regional, and national levels. Other Life Options publications include booklets on exercise, education, and employment for dialysis patients. In 2002, Life Options launched Kidney School (www.kidneyschool.org), a patient education website with 10 modules on how kidneys work, treatment modalities, vascular access, lab tests, nutrition, and other topics. Two more modules on sexuality and staying active have been added, and four others are planned.

National Black Nurses Association



www.nbna.org

The National Black Nurses Association (NBNA) provides a forum for collective action by nurses to investigate, define, and advocate for the health care needs of African Americans and to implement strategies that ensure access to health care that matches or exceeds the health care standards of the larger society. In addition to promoting the nursing profession through education and mentoring programs, NBNA works to build consumer knowledge and understanding of health care issues. In 2002, NBNA joined a coalition supporting a national public health initiative to help the more than 17 million Americans who have diabetes achieve their target blood glucose levels.

National Kidney Foundation



www.kidney.org

The National Kidney Foundation (NKF) works to prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation. The NKF's goals include public education, as well as fundraising and support for research and professional development. The Kidney Disease Outcomes Quality Initiative (K/DOQI) is a patient outcomes improvement program that develops clinical practice guidelines. The K/DOQI Learning System is a new umbrella program for NKF education programs. It is designed to ensure that all information is grounded in the scientific base established by the K/DOQI guidelines. The NKF's education programs include the Kidney Early Evaluation Program (KEEP), which provides free health screenings for the early warning signs of kidney disease, and Rehabilitation, Information, Support, and Empowerment (RISE), which helps dialysis patients resume meaningful daily activities.

Polycystic Kidney Disease Foundation



www.pkdcure.org

The Polycystic Kidney Disease (PKD) Foundation promotes research to find a cure and improve the care and treatment of those who have the disease. The organization publishes *PKD Progress* magazine to disseminate the latest research developments, report on health policy issues, provide patient information, and promote foundation activities. The organization has translated basic PKD information into 16 languages. In 2002, the foundation created a public service announcement (PSA) campaign to help raise awareness of PKD. The campaign, which includes print, radio, and television elements, was designed to create a broader web of PKD awareness and to guide people to the foundation for further information. PSA distribution will begin in 2003.

Renal Physicians Association



www.renalmid.org

The Renal Physicians Association (RPA) represents nephrologists, practice managers, advance practice nurses, and physician assistants in their pursuit and delivery of quality renal health care. The RPA has published nearly 40 position papers on issues ranging from insurance coverage for daily hemodialysis to ways to deal with the dwindling workforce of nephrologists and nurses. The RPA's three clinical practice guidelines cover hemodialysis adequacy, shared decisionmaking in the appropriate initiation of and withdrawal from dialysis, and patient preparation for renal replacement therapy.

The Simon Foundation for Continence



www.simonfoundation.org

The Simon Foundation is a not-for-profit educational organization dedicated to providing assistance and support to those experiencing urinary incontinence. The foundation publishes the *Informer*, a newsletter on continence issues, organizes self-help groups, and advises manufacturers and medical researchers on patients. The foundation published *Managing*

Incontinence, a book for the lay audience. The *I Will Manage* program provides health professionals with the resources to organize local support groups. The program kit includes promotional materials, guidelines for conducting support sessions, and participant course materials.

Society of Urologic Nurses and Associates

www.suna.org



The Society of Urologic Nurses and Associates (SUNA) is a professional organization committed to excellence

in patient care standards and a continuum of quality care, clinical practice, and research through education of its members, patients, families, and communities. SUNA has developed eight new patient fact sheets on benign prostatic hyperplasia, chlamydia, genital warts, IC, kidney stones, local estrogen replacement, prostatitis, and urinary tract infections. The fact sheets will be published in SUNA's *Journal of Urologic Nursing*.

United Network for Organ Sharing

www.unos.org

www.transplantliving.org



The United Network for Organ Sharing (UNOS) is a nonprofit scientific

and educational organization that administers the nation's Organ Procurement and Transplantation Network (OPTN), established by the Congress in 1984. As the OPTN administrator, UNOS collects and manages data about every transplant occurring in the United States, facilitates the organ matching and placement process, and consults medical professionals, transplant recipients, and donor families to develop organ transplantation policy. UNOS publishes the *UNOS Update* newsletter, fact sheets on various topics relating to transplantation, bioethics white papers, and patient brochures. The new UNOS patient website, www.transplantliving.org, includes sections called Transplant 101, Organ Data Source, Living Donation, Resources, and Data. ■

chronic kidney, urologic, and hematologic diseases. The program coordinates and monitors patient recruitment and adherence to interventions.

Three new clinical trials have begun recruiting patients at participating centers around the country.

CRIC, MIST, and DAC are the acronyms that stand for the new programs in chronic renal insufficiency (also called chronic kidney disease), treatments for benign prostatic hyperplasia (BPH), and vascular access for hemodialysis, respectively.

Chronic Renal Insufficiency Cohort (CRIC) Study

End-stage renal disease (ESRD) is an important medical and public health problem in the United States, and it disproportionately affects racial and ethnic minority groups, particularly African Americans, American Indians, and Hispanics. African Americans and American Indians are four times as likely as whites, and Hispanics are twice as likely as whites, to develop kidney failure, which requires dialysis or kidney transplantation for survival.

In 2000, almost 100,000 people with chronic kidney disease entered ESRD, with the result that approximately 300,000 people were sustained on hemodialysis while 80,000 had functioning transplants. These numbers have doubled since 1990, and they are expected to nearly double again by 2010. The increase in the number of Americans with ESRD is directly proportional to the increase in the number of Americans with type 2 diabetes, a major cause of chronic renal insufficiency. Another major cause is hypertension. The leading cause of death in patients with ESRD is cardiovascular disease.

The factors that contribute to the decline in kidney function and the development of cardiovascular disease in people with chronic renal insufficiency are unknown, and further research is needed before interventions can be evaluated and implemented. To date, few studies have focused on people whose chronic kidney disease has not yet developed into ESRD. Only a small number of studies have been conducted, and all have had significant methodological shortcomings.

One type of study that has played an important role in defining risk factors for a wide range of diseases is the prospective cohort study. To determine the risk factors for rapid decline in kidney function and development of cardiovascular disease, the NIDDK established the CRIC Study, a 7-year prospective, multiethnic, multiracial study of approximately 3,000 patients with chronic renal insufficiency. Participants will reflect the racial, ethnic, and gender composition of the U.S. ESRD population. The data and specimens obtained from people in this study will serve as a national resource for investigating chronic renal as well as cardiovascular disease. Establishing this cohort of patients and following them prospectively will also provide an opportunity to examine genetic, environmental, behavioral, nutritional, quality-of-life, and health resource utilization factors in this population.

Seven clinical centers are participating in the study: University of Pennsylvania, Philadelphia; University of Maryland–Johns Hopkins, Balti-

more; University of Illinois at Chicago Clinical Centers; University of Michigan, Ann Arbor; University of California, Kaiser Permanente of Northern California/University of California, San Francisco; Tulane University, New Orleans; and Case Western Reserve University, Cleveland.

Protocol development for the CRIC study began in September 2001. The recruitment stage, begun in 2003, will continue into early 2005. The main part of the study will consist of regular clinic visits for followup and monitoring of patients so that renal function can be measured and cardiovascular studies and laboratory tests can be performed. In addition, participants will answer questionnaires to assess various demographic, nutritional, and quality-of-life factors. Followup and data collection on cohort study participants who develop ESRD will be performed after they start renal replacement therapy (renal transplantation, hemodialysis, or peritoneal dialysis), with modification of data collection, measurements, and followup visits as necessary and as described in the protocol. Final data analysis and closeout are scheduled for 2008. Thomas Hostetter, M.D., is the project officer.

Minimally Invasive Surgical Therapies (MIST) Treatment Consortium for BPH

KUH has had a substantial and longstanding interest in evaluating the effectiveness of strategies for treating BPH. For many years, transurethral resection of the prostate (TURP) has been the surgical standard for this condition; however, over the past decade, a number of technical innovations have allowed the development of new surgical treatments that aim to achieve the same long-term outcomes as TURP but with less morbidity, lower cost, shorter hospital stay, and more rapid recovery. These new, minimally invasive surgical approaches funded by the NIDDK include laser therapy, hyperthermia and thermotherapy, transurethral electrovaporization, microwave therapy, and transurethral needle ablation. New techniques are appearing regularly. The quality of published reports on the outcomes of these minimally invasive therapies are highly

variable, and rigorous randomized clinical trials have only rarely been conducted.

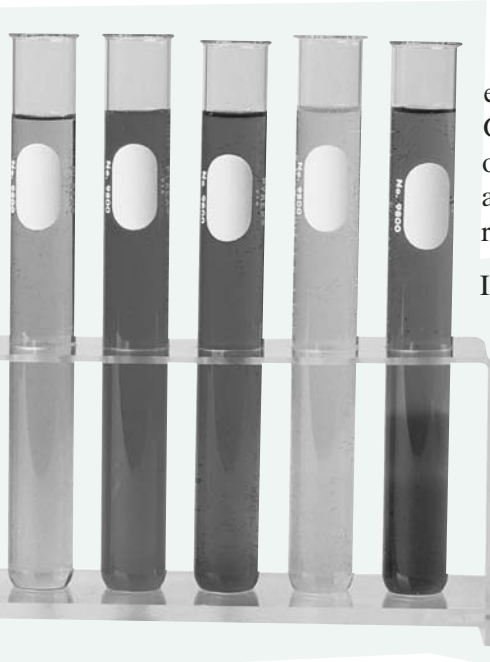
To assess the long-term safety and effectiveness of these new therapies, the NIDDK has formed a group of seven collaborative Prostate Evaluation Treatment Centers and a Biostatistical Coordinating Center to develop and conduct randomized, controlled clinical trials that will give a clearer picture of the benefits and risks of these methods. The first trial to be conducted by the MIST consortium will evaluate the safety and effectiveness of transurethral needle ablation (TUNA), transurethral microwave therapy (TUMT), and medical therapy with an alpha-blocker and finasteride combined. The results of this first trial will provide both physicians and patients with the knowledge needed to make the most appropriate choices for long-term management of BPH. Leroy Nyberg, Ph.D., M.D., is the project officer.

Dialysis Access Consortium (DAC)

Maintenance of vascular access for hemodialysis is one of the major challenges in caring for the hemodialysis patient. Access-related problems are among the most frequent reasons for hospitalization in the ESRD population, and the cost of vascular access placement and repair in the United States exceeds \$700 million per year. In fiscal year 2000, NIDDK established the Dialysis Access Consortium, which consists of seven clinical centers and a data coordinating center, to undertake interventional clinical trials to improve outcomes in patients with fistulas and grafts. Two randomized placebo-controlled clinical trials have been designed and have begun recruiting patients. The first trial will evaluate the effects of the antiplatelet agent clopidogrel on prevention of early fistula failure. A second clinical trial will study Aggrenox, with the goal of preventing access stenosis in hemodialysis patients with grafts. Catherine Meyers, M.D., is the project officer.

For more information about these trials, call KUH at (301) 594-7717 and ask to speak with the project officer or Dr. Kusek. ■

GFR CALCULATION, *continued from page 1*



National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), developed a GFR calculation that requires only a serum creatinine value along with the patient's weight, race, and sex.

In addition to making monitoring a patient's kidney function easier, the MDRD GFR calculation has allowed researchers to use data from the National Health and Nutrition Examination Survey to estimate the prevalence of chronic kidney disease in the United States.

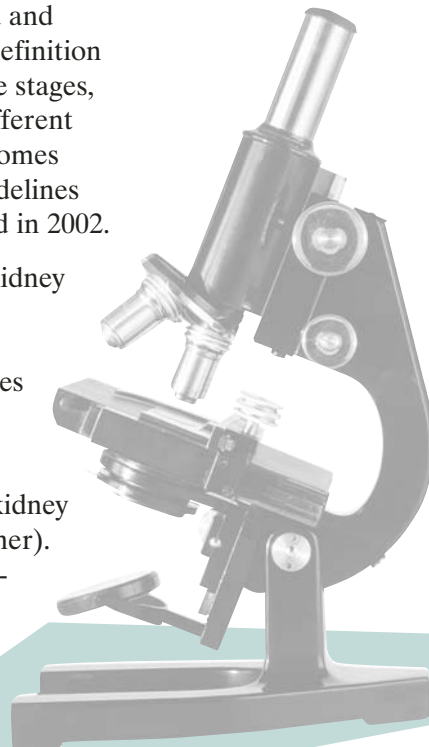
The National Kidney Foundation (NKF) has used the GFR formula and prevalence estimates to develop a clear definition of chronic kidney disease, identify disease stages, and offer treatment guidelines for the different stages. The NKF's Kidney Disease Outcomes Quality Initiative (K/DOQI) practice guidelines for chronic kidney disease were published in 2002.

The K/DOQI guidelines define chronic kidney disease as a GFR that remains below 60 mL/min/1.73 m² for more than 3 months. The new guidelines also identify five stages of the disease and recommend actions to take at each stage.

- Stage 1 comprises patients who have kidney damage but a normal GFR (90 or higher). The recommended actions are to diagnose and treat the cause of the kidney damage, treat comorbid conditions, slow the progression of chronic kidney disease, and reduce cardiovascular risk factors.

- Stage 2 comprises patients with a mild reduction in GFR (60 to 89). The recommended action is to estimate disease progression.
- Stage 3 consists of a moderate GFR reduction (30 to 59). The recommended actions are to evaluate and treat complications such as anemia and bone disease.
- Stage 4 consists of a severe GFR reduction (15 to 29). The recommended action is to prepare the patient for kidney replacement therapy.
- Stage 5 consists of kidney failure, marked by a GFR below 15. The recommended action is to initiate kidney replacement therapy—either dialysis or transplantation—if uremia is present.

NIDDK scientists and NKF officials urge medical laboratories to provide a GFR value based on serum creatinine in routine blood analyses. ■



New Publications From NKUDIC

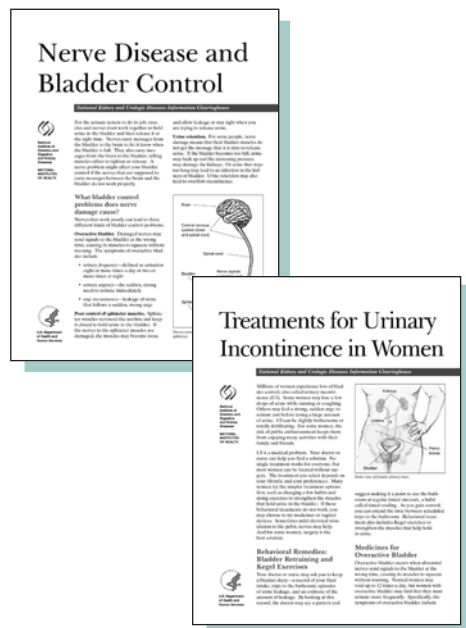
The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is pleased to announce several new and updated publications. Most NKUDIC materials are available online at www.kidney.niddk.nih.gov or www.urologic.niddk.nih.gov, and printed versions can be ordered at www.catalog.niddk.nih.gov or by using the form on page 15. Since NKUDIC's health information materials are a public service and are not copyrighted, health care professionals are encouraged to duplicate these publications as handouts for their patients or as an insert for office or association newsletters.

New Materials

Nerve Disease and Bladder Control. This fact sheet explains overactive bladder, detrusor-sphincter dyssynergia, and urine retention and discusses the symptoms, causes, diagnosis, and treatment of neurogenic bladder.

Treatments for Urinary Incontinence in Women.

This fact sheet focuses on drug therapy and surgery. It also explains the differences between urge and stress incontinence and how the type of incontinence affects treatment choice.



New in Spanish

Eat Right to Feel Right on Hemodialysis (booklet)

Erectile Dysfunction (fact sheet)

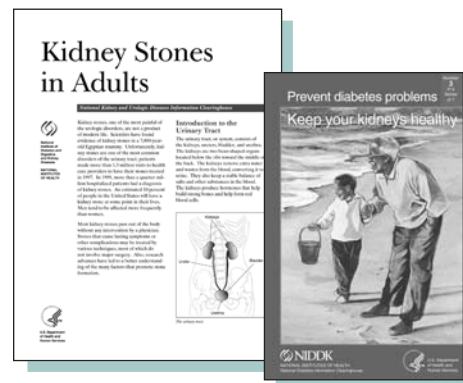
Your Kidneys and How They Work (fact sheet)



Updated and Reprinted Materials

Kidney Stones in Adults (fact sheet)

Prevent Diabetes Problems: Keep Your Kidneys Healthy (booklet)



Updated Information Packets

Congenital Anomalies

Kidney Disease and African Americans

Medullary Sponge Kidney

Urinary Reflux Disorders in Children ■

NKF's New Study Shows Possible Links Between Smoking and Kidney Disease

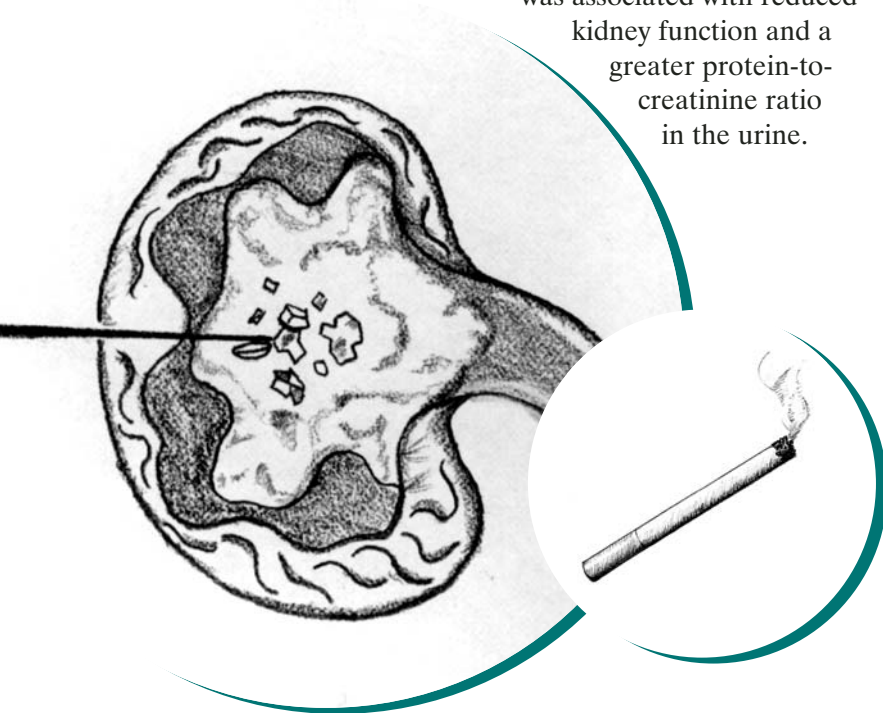
According to a new study reported in the *American Journal of Kidney Disease*, the official publication of the National Kidney Foundation (NKF), smoking may lead to kidney damage, even in healthy people. Earlier studies showed an association between smoking and the development or progression of kidney disease in people who already had high blood pressure or diabetes. The new study compared smoking habits and indicators of kidney disease such as reduced kidney function or protein in the urine. The study group of more than 11,000 adults had normal blood pressure and glucose metabolism.

Men who smoked were three times as likely as nonsmokers to have reduced kidney function, indicated by a glomerular filtration rate (a measure of kidney function) below 60 milliliters per minute. People who had high normal blood pressure or blood glucose levels had an increased likelihood of protein in their urine. There was also a relationship between the cumulative amount of smoking and kidney damage. Lifetime smoking, but not current level of smoking, was associated with reduced kidney function and a greater protein-to-creatinine ratio in the urine.

"These are important findings," said Brian J.G. Pereira, M.D., president of the National Kidney Foundation. "Smoking has been implicated as a risk factor for development and progression of kidney disease in people with conditions such as diabetes or high blood pressure," he stated, "but the effect of smoking on kidney function in the healthy population has been less clear. These results suggest that healthy adults who smoke may be at increased risk for developing chronic kidney disease."

Earlier research has suggested possible ways smoking could result in kidney damage, including promotion of atherosclerosis, or hardening of the arteries, in the kidneys; changes in blood circulation in the kidneys; and effects on the function of the endothelial cells, which line the blood vessels and heart. These changes could mean that less blood reaches important kidney cells, leading to cell damage.

For more information about chronic kidney disease, contact the NKF at 1-800-622-9010 or online at www.kidney.org. The NKF is a major voluntary health organization seeking to prevent kidney and urologic diseases, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation. ■



New in CHID

CHID_{online}

Each quarter, the National Kidney and Urologic Diseases Information Clearinghouse adds about 150 items to the kidney and urologic diseases (KU) subfile of the Combined Health Information Database (CHID). This database contains abstracts and ordering information for professional resources and patient education materials—such as books, pamphlets, videos, journal articles, and manuals—dealing with a variety of kidney and urologic topics. Recently, the KU subfile has begun to include resources available on the World Wide Web. CHID Online can be accessed at <http://chid.nih.gov> on the Internet. Among recent additions to the KU subfile are these materials on kidney disease in children and treatments for pain in interstitial cystitis.

Kidneys and Urinary Tract (for Teens)

The Nemours Foundation supports a number of children's health facilities and medical research programs, as well as the Nemours Center for Children's Health Media and the



KidsHealth website, which contains articles on a variety of health topics written in different styles to appeal to parents, teenagers, and kids. Searching on terms like “kidney” or “urinary” in the *KidsHealth* search engine yields several entries for each audience. *Kidneys and Urinary Tract*

(*for Teens*) provides basic information about the anatomy of the urinary tract and the functions of the kidneys, ureters, bladder, and urethra. The article explains why the kidneys and urinary tract are important and describes diseases that hinder them, including urinary tract infections, kidney stones, vesicoureteral reflux, kidney failure, nephrotic syndrome, high blood pressure, and Wilm's tumor.

Kidneys and Urinary Tract (for Teens) can be accessed at www.kidshealth.org.

Interstitial Cystitis and Pain

This fact sheet from the Interstitial Cystitis Association (ICA) reviews pharmacologic and nonphar-



macologic treatments to relieve or minimize the pain of interstitial cystitis (IC). Drugs used to treat IC pain include nonopioid medications (aspirin, acetaminophen, and NSAIDs), tricyclic antidepressants, pentosan polysulfate sodium (Elmiron), local anesthetics, anticonvulsants, benzodiazepines, antihistamines, tramadol (Ultram), and opioid medications. Nonpharmacologic treatments include diet modification, physical therapy, acupuncture, transcutaneous electric nerve stimulation, biofeedback, hypnosis, and cognitive therapy.

Single copies of *Interstitial Cystitis and Pain* are available for \$1.25 to the public, \$1 for ICA members. The brochure is available from the Interstitial Cystitis Association, 110 North Washington Street, Suite 340, Rockville, MD 20850. Phone: (301) 610-5300. The publication can also be ordered online at www.ichelp.org. ■

NKDEP Launches Programs to Prevent Kidney Disease Among African Americans

Atlanta, Baltimore, Cleveland, and Jackson, MS, Serve as Testing Grounds

June marked the launch of the first NIH pilot education program to increase awareness about kidney disease and promote early testing among African Americans, who are among those hardest hit by kidney disease. The National Kidney Disease Education Program (NKDEP) and its partners held the kick-off during the Steering Committee meeting on June 20, 2003, in Bethesda, Maryland.

You Have the Power to Prevent Kidney Disease is a year-long pilot program in four cities—Atlanta, Baltimore, Cleveland, and Jackson, Mississippi—chosen for their relatively large African American communities and their existing resources. Local coalitions are working through the media, through dialysis patients and their families, and through other outlets to encourage people at high risk for kidney disease to be tested and to learn about treatments that can help them avoid end-stage renal disease.

“This education program has been built with members of the communities it aims to serve, so its messages—that kidney disease can be prevented and treated—are on target to reach the people who most need to know,” says Griffin Rodgers, M.D., deputy director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health, U.S. Department of Health and Human Services, which supports NKDEP.

Janice Lea, M.D., assistant professor of medicine at Emory University and co-chair of the NKDEP Atlanta Coalition said, “The number one goal of our coalition is to make African Americans, who are disproportionately represented among those with kidney disease, aware of the risks of kidney disease, to encourage them to talk to their physicians about kidney disease, and to get tested if they are at risk.”

According to national statistics, African Americans make up 12 percent of the U.S. population, but account for about 30 percent of those with

kidney failure. Approximately 20 million Americans have kidney disease, and some 400,000 have kidney failure requiring dialysis or a kidney transplant to stay alive. That figure is expected to double in the next 10 years.

The *You Have the Power to Prevent Kidney Disease* campaign stresses that

- Early detection is important. If you have diabetes, hypertension, or a family history of kidney failure, you are at risk. Talk to your doctor about having your kidneys checked.
- Effective treatment can prevent or slow kidney damage.
- Left undiagnosed and untreated, kidney disease can lead to kidney failure.

Diabetes and hypertension are directly linked to kidney disease. According to the U.S. Renal Data System, about 75 percent of the African Americans who have kidney failure also have diabetes or hypertension. People who have any risk factor at all should be tested for kidney disease.

“People just don’t make the connection between their diabetes or their high blood pressure and kidney disease, and they are from families riddled with these problems,” said Thomas Hostetter, M.D., director of NKDEP. He then observed that this lack of understanding serves as “clear evidence of the desperate need to help people become more literate about their health.”

NKDEP will evaluate the effectiveness of its pilot efforts by measuring changes in knowledge, attitudes, beliefs, and practices through two surveys, one conducted before the campaign’s launch and a second a year later. The program will also monitor audience and media reactions to events and materials.

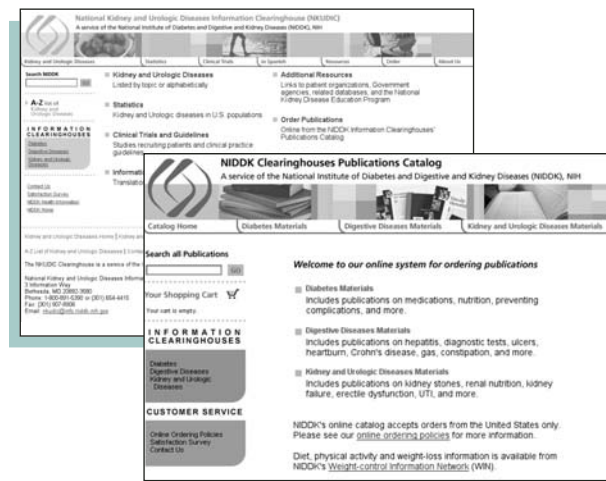
The program’s 30 partners include both public agencies and private organizations.

For more information, visit the national NKDEP website at www.nkdep.nih.gov. ■

What You Need to Know About NKUDIC Online

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) has a new look and a new way to order publications. You can see our new colors, design, and navigation features at either of two streamlined addresses: www.kidney.niddk.nih.gov or www.urologic.niddk.nih.gov.

Many customers of NKUDIC have asked to order publications online and to use credit cards to pay for bulk orders. Now they can. The NIDDK has also launched the NIDDK publications catalog website at www.catalog.niddk.nih.gov, where folks can fill their shopping carts with free single copies or low-cost bulk orders for their practices and clinics and pay with plastic. ■



Upcoming Conferences and Workshops

Research Insights Into Interstitial Cystitis: A Basic and Clinical Science Symposium



October 30–
November 1,
2003

Contact: Iain Mackenzie
imackenzie@thehillgroup.com
Date: October 30–
November 1, 2003

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Interstitial Cystitis Association (ICA) are sponsoring this scientific meeting in the Washington, DC, area. Scientific topics include bladder urothelium, developmental biology of the bladder, epidemiology and genetics, visceral pain, bladder neurophysiology, clinical studies, urinary markers, and more. The meeting will include invited state-of-the-art lectures, podium presentations, panel discussions, and poster sessions. Additional information can be found on the NIDDK website at www.niddk.nih.gov/fund/other/conferences.htm.

Urologic Complications of Diabetes

Contact: Aimee Benton
abenton@thehillgroup.com
Date: December 3–4, 2003



December 3–4,
2003

The NIDDK will convene an international group of clinical and basic researchers to discuss urologic complications of diabetes, including bladder, sexual, and erectile dysfunction, as well as urinary tract infections. The meeting is planned as a series of short presentations on current understanding, knowledge gaps, and future directions for research on urologic complications among men and women with diabetes. The relatively small size of this meeting is designed to facilitate the formation of international collaborative research working groups and initiate new areas of research. Organizers anticipate that an NIDDK program announcement will eventually result from this meeting. ■

NKUDIC Publications List

Patient Education Fact Sheets

Single copies free. Packages of 25, \$5 each.

KU-145	Amyloidosis and Kidney Disease
KU-146	Anemia in Kidney Disease and Dialysis
KU-141	Childhood Nephrotic Syndrome
KU-155	Cystoscopy and Uteroscopy
KU-133	Diabetes Insipidus
KU-99	Erectile Dysfunction
KU-147	Financial Help for Treatment of Kidney Failure
KU-135	Glomerular Diseases
KU-182	Growth Failure in Children With Kidney Disease
KU-148	Hemodialysis Dose and Adequacy
KU-181	Hemolytic Uremic Syndrome
KU-157	High Blood Pressure and Kidney Disease
KU-72	Interstitial Cystitis
KU-156	Kidney Biopsy
KU-93	Kidney Disease of Diabetes
KU-04	Kidney Stones in Adults
KU-164	Medical Tests for Prostate Problems
KU-178	Nerve Disease and Bladder Control
KU-180	Overview of Kidney Disease in Children
KU-149	Peritoneal Dialysis Dose and Adequacy
KU-91	Peyronie's Disease
KU-105	Polycystic Kidney Disease
KU-22	Prostate Enlargement: Benign Prostatic Hyperplasia (BPH)
KU-118	Proteinuria
KU-150	Renal Osteodystrophy
KU-87	Renal Tubular Acidosis
KU-183	School and Family Problems of Children With Kidney Failure
KU-179	Treatment for Urinary Incontinence in Women
KU-184	Treatment Methods for Kidney Failure in Children
KU-119	Urinary Incontinence in Children
KU-121	Urinary Incontinence in Women
KU-03	Urinary Tract Infection in Adults
KU-120	Urinary Tract Infections in Children
KU-166	Urodynamic Testing
KU-140	Vascular Access for Hemodialysis
KU-144	What Your Female Patients Want To Know About Bladder Control
KU-131	Your Kidneys and How They Work
KU-132	Your Urinary System and How It Works

Patient Education Booklets (Easy-to-Read)

Single copies free. Packages of 25, \$10 each.

KU-109	Bladder Control for Women
KU-134	Eat Right to Feel Right on Hemodialysis
KU-110	Exercising Your Pelvic Muscles
KU-138	The Kidney Diseases Dictionary
KU-50	Kidney Failure: Choosing a Treatment That's Right for You
KU-151	Kidney Failure Glossary
KU-111	Menopause and Bladder Control
KU-112	Pregnancy, Childbirth, and Bladder Control
KU-142	Prevent Diabetes Problems: Keep Your Kidneys Healthy
KU-113	Talking to Your Health Care Team About Bladder Control

Treatment Methods for Kidney Failure:

KU-152	Hemodialysis
KU-153	Peritoneal Dialysis
KU-154	Transplantation
KU-139	The Urologic Diseases Dictionary
KU-127	What Are Kidney Stones?

What I need to know about

KU-167	Prostate Problems
KU-168	Urinary Tract Infections
KU-114	Your Body's Design for Bladder Control
KU-115	Your Medicines and Bladder Control

Boxed Sets and Kits

First boxed set or kit free.

BCW-C	Bladder Control for Women Patient Kit (Additional kits, \$5 each.)
BCW-P	Bladder Control for Women Professional Kit (Additional kits, \$5 each.)

KU-210	Treatment Methods for Kidney Failure Series Boxed Set (Additional boxed sets, \$10 each.)
--------	--

Spanish Materials

Single copies free. Packages of 25, \$10 each unless otherwise stated.

KU-136	Bladder Control for Women
KU-129	Erectile Dysfunction (Packages of 25, \$5 each.)
KU-158	Exercising Your Pelvic Muscles
KU-169	High Blood Pressure and Kidney Disease (Packages of 25, \$5 each.)
KU-170	Kidney Disease of Diabetes (Packages of 25, \$5 each.)
KU-54	Kidney Failure: Choosing a Treatment That's Right for You
KU-176	Kidney Failure: Eat Right to Feel Right on Hemodialysis
KU-159	Menopause and Bladder Control
KU-160	Pregnancy, Childbirth, and Bladder Control
KU-174	Prevent Diabetes Problems: Keep Your Kidneys Healthy
KU-130	Talking to Your Health Care Team About Bladder Control
KU-163	What I need to know about Kidney Stones
KU-161	Your Body's Design for Bladder Control
KU-175	Your Kidneys and How They Work (Packages of 25, \$5 each.)
KU-162	Your Medicines and Bladder Control

Statistics

KU-104	Kidney and Urologic Diseases Statistics for the United States (Single printed copies free to those without Internet access.)
KU-96	United States Renal Data System 2002 Annual Data Report (Book, \$10)
KU-96CD	United States Renal Data System 2002 Annual Data Report (CD-ROM, \$5)

Research-Focused Materials

Single copies free. Additional copies, \$1 each. Call for bulk quantities.

KU-185	Overcoming Bladder Disease: A Strategic Plan for Research
KU-137	Progress and Priorities: Renal Disease Research Plan
KU-143	Research Needs in Pediatric Kidney Disease: 2000 and Beyond

Information Packets

Single copies free. No bulk orders.

KU-177	Congenital Anomalies
KU-65	Kidney Disease and African Americans
KU-84	Medullary Sponge Kidney
KU-128	Nutrition and Kidney Disease
KU-100	Urethritis
KU-123	Urinary Incontinence in Men
KU-70	Urinary Reflux Disorders in Children

Online Publications

Single printed copies free to those without Internet access.

KUI-12	Analgesic Nephropathy
KUI-13	Cystocele
KUI-16	Goodpasture Syndrome
KUI-18	Hematuria
KUI-03	IgA Nephropathy
KUI-06	Lupus Nephritis
KUI-07	Nephrotic Syndrome in Adults
KUI-02	Prostatitis
KUI-04	Pyelonephritis
KUI-11	Simple Kidney Cysts
KUI-08	Vesicoureteral Reflux

Other Materials

Single copies free unless otherwise stated.

BCW-S	Bladder Control for Women Poster (First 25 posters free. Additional posters, \$1 each.)
KU-19	Directory of Kidney and Urologic Diseases Organizations
KU-08	National Kidney and Urologic Diseases Information Clearinghouse brochure
KU-17	Research Updates in Kidney and Urologic Health

Catalog/Searches

Single copies free.

NIDDK-02	NIDDK Information Clearinghouses Publications Catalog
KUS-100	Searches-On-File: Topics in Kidney and Urologic Diseases

NKUDIC

National Kidney and Urologic Diseases Information Clearinghouse Order Form

Please photocopy this order form for future orders.

[illegible]

Method of Payment

Total

Check or money order enclosed _____

Purchase order enclosed

Credit card number

VISA MasterCard

Expiration date / (Month/Year)

Card holder signature _____

Check this box if you would like to receive the *Research Updates in Kidney and Urologic Health* newsletter. Subscription is free, but available to health professionals only.

Please print
clearly and
provide all
necessary
mailing
information.
Make checks
payable to
NKUDIC.
Please do not
send cash.

Name _____

Title _____

Customer ID #* (if applicable)

Organization

Address

City _____ State _____ ZIP _____

Phone	Email
-------	-------

*Please see the packing slip from your most recent order. Shipping and handling are subject to change without prior notice.

Please return this order form to NKUDIC, 3 Information Way, Bethesda, MD 20892-3580 • fax: (301) 634-0716

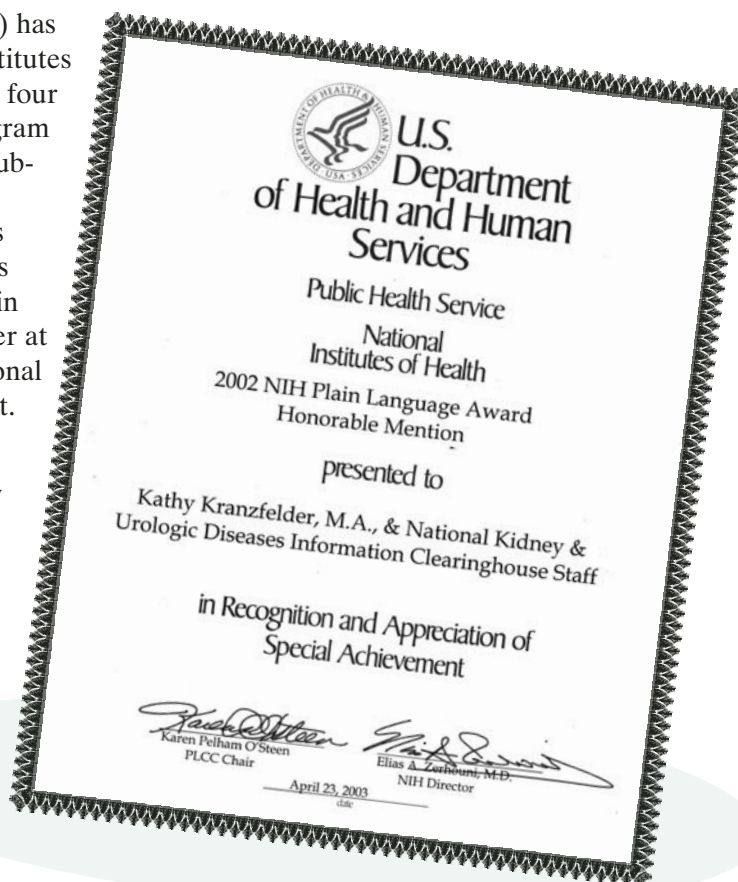
CUT ALONG LINE OR PHOTOCOPY AND COMPLETE.



NKUDIC Wins Plain Language Awards

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) has won recognition from the National Institutes of Health (NIH) Plain Language Initiative for four recent publications. NIH established the program to promote clear, concise writing in all NIH publications produced for the public. Every year, the program evaluates nominated publications produced by the various Institutes and Centers within NIH and selects the best to receive Plain Language Awards. This year's keynote speaker at the award ceremony was Cokie Roberts, National Public Radio and ABC political correspondent.

In April 2003, the Plain Language Initiative announced that four publications produced by NKUDIC had received honorable mention awards: *What I Need to Know About Prostate Problems*, *Medical Tests for Prostate Problems*, *High Blood Pressure and Kidney Disease*, and the *Urologic Diseases Dictionary*. These and other NKUDIC publications can be viewed on the new NKUDIC website at www.kidney.niddk.nih.gov or www.urologic.niddk.nih.gov. Printed copies can be ordered at www.catalog.niddk.nih.gov or by using the form on page 15 of this newsletter. ■



National Kidney and Urologic Diseases
Information Clearinghouse
3 INFORMATION WAY
BETHESDA, MD 20892-3580

OFFICIAL BUSINESS
Penalty for private use, \$300

Do not forward
Address Service Requested
Return Postage Guaranteed

Presorted Standard Mail
Postage & Fees Paid
NIH/NIDDK
Permit No. G-810